

After pregnancy loss, Internet forums help women understand they are not alone

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Nearly one in six pregnancies end in miscarriage or stillbirth, but parents' losses are frequently minimized or not acknowledged by friends, family or the community.

"Women who have not gone through a stillbirth don't want to hear about my birth, or what my daughter looked like, or anything about my experience," said one woman, responding in a University of Michigan Health System-led study that explored how Internet communities and message boards increasingly provide a place for women to share feelings about these life-altering experiences.

The [anonymous survey](#) of more than 1,000 women on 18 message boards opens a new window into who is using the forums and why. The findings will be published in *Women's* [Health Issues](#).

The researchers were surprised to find that only half of the women surveyed were in their first year of loss after a pregnancy. Many were still coping with the emotional impacts five, 10 and even 20 years later.

"To my family and most friends, the twins have been gone for nearly a year and are entirely a subject for the past," another woman wrote.

A second unexpected finding was that only 2 percent of survey respondents were African American, despite nearly 60 percent of [African Americans](#) having internet access and despite [black women](#) having twice the risk of [stillbirth](#) as [white women](#).

"This is the largest study to look at who uses Internet message boards after a [pregnancy loss](#) and it demonstrates a significant [disparity](#) between the women who experience loss and those who responded to the survey," says lead study author Katherine J. Gold, M.D., M.S.W., M.S., assistant professor of [family medicine](#) at the U-M Medical School. "This suggests an important gap in support for African American parents that should be explored further."

By far, the most common reason women gave for participating in the message boards was that it helped them to feel that their experience wasn't unique.

One woman explained that the most important aspect of the forums was knowing "that I am not the only one this has happened to and that I am not alone in this horrible nightmare."

Another common theme was that the online environments provided a safe and validating space for the women to express themselves. Others appreciated the ease and convenience of the Internet and their ability to spend more time composing their thoughts than they would be able to in a face-to-face conversation.

Most participants agreed that boards should have a moderator or facilitator, and that health care professionals should participate. Of the 908 women who answered the question, 82 percent said they had learned new medical information from one of the forums.

"The fact that so many women learned new medical information from the message boards shows what an important resource they can be in this regard," says study senior author Christie Palladino, M.D., M.Sc., an obstetrician/gynecologist with Georgia Health Sciences University's Education Discovery Institute.

Gold and her colleagues are currently pursuing similar research with bereaved parents who attend in-person support groups and plan to compare and contrast the results.

More information: "Internet Message Boards for Pregnancy Loss: Who's On-Line and Why?," Women's Health Issues, [doi:10.1016/j.whi.2011.07.006](https://doi.org/10.1016/j.whi.2011.07.006)

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